

Ask Me Anything ALS - Participating in Clinical Trials

While there are currently no cures for ALS, there are numerous clinical trials taking place right now across the country with a goal of finding safe and effective therapies for ALS. With the many opportunities available, finding the right fit and participating in a clinical trial can be overwhelming and confusing.

You and your loved one may be weighing why you should participate, which trial to pick and what to expect. The I AM ALS Clinical Trials Community Team hosted a conversation on participating in clinical trials through the <u>I AM ALS Ask Me Anything ALS series</u> to help answer some of your burning questions on identifying and preparing for a clinical trial, what to expect when participating in a clinical trial, and more. This resource was created as a result of conversations had and resources shared during the event.

Resources

- ALS Clinical Trial Resources I AM ALS
 - <u>Description</u>: This page offers different clinical trial related information and resources from leading ALS and research organizations.
- ALS Clinical Trial Checklists | AM ALS
 - <u>Description</u>: This checklist offers questions to ask one's ALS care team to learn more about clinical trials, the associated benefits and risks, and help identify trials that they may be able to participate in.
- Checklist of Questions to Ask About a Specific Clinical Trial | AM ALS
 - <u>Description:</u> This checklist offers questions to ask a person's ALS care team to learn more about a specific trial of interest.
- ALS Treatments and Trials I AM ALS
 - Description: This resource shares information about FDA-approved treatments, clinical trials and supplements for ALS.
- Clinical Trial Finder Tools
 - <u>Description</u>: These tools help users find and learn more about ALS clinical trials and research opportunities across the globe.
 - ALS Signal I AM ALS
 - <u>Clinical Trial Finder Tool</u> ALS Therapy Development Institute (ALS TDI)
 - NEALS Clinical Trial Tool Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS)
 - <u>Clinicaltrials.gov</u> National Institute of Health

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- **<u>ALSUntangled</u>** ALS Physicians & Researchers
 - <u>Description</u>: Created by Dr. Richard Bedlack from Duke University and sponsored by The ALS Association, this website shares physicians' reviews of alternative and off-label treatments for ALS.
- ALS Clinical Research Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS)
 - <u>Description</u>: This article offers information about ALS clinical research, related definitions, how to get involved, and more.
- Igniting Innovation Through Research & Trials Massachusetts General Hospital & AMG Center for ALS
 - <u>Description</u>: This article discusses the importance of ALS clinical research, the steps Massachusetts General Hospital and the AMG Center for ALS are taking to support these efforts, and their research infrastructure.

Relevant ALS Facebook Groups

The information posted in Facebook groups does not represent the views of I AM ALS and has not been verified by us. Please discuss questions and decisions related to your diagnosis and medical care with your health care team.

- <u>ALS Clinical Trials and Research</u>
 - <u>Description</u>: This group is dedicated to helping people understand the processes that lead to drug approval, and to share information about upcoming clinical trials and evidence-based research papers about ALS.
- ALS Radicava User Group
 - <u>Description:</u> This is a community-run group dedicated to discussing the FDA-approved ALS drug, Radicava, (Edaravone).

Additional Learning Opportunities

- Ask Me Anything ALS Participating in Clinical Trials Event Recording | AM ALS
 - <u>Description</u>: The Ask Me Anything ALS Participating in Clinical Trials event focused on how and why panelists decided to get involved in ALS clinical research, what their experiences have been like, insight from professionals working within the space and more.
 - Event Recording
- Tim Lowrey Panel Series | AM ALS
 - <u>Description</u>: This panel joins classes, groups and other events to share about ALS, and explore potential ways the group may be impacted by the disease within their careers.
- I AM ALS Clinical Trials Community Team | AM ALS
 - <u>Description:</u> The Clinical Trials Team partners with researchers, government agencies and drug sponsors to ensure access, efficiency and humaneness of ALS therapy development and approval. It collects and distributes information regarding clinical trials to the ALS community.